



Communication change in ALS: Engaging people living with ALS and their partners in future research

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Communication change in ALS: Engaging people living with ALS and their partners in future research

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Communication change in ALS: Engaging people with ALS dysarthria in future research

Objective: To involve people living with ALS (plwALS) in the scoping and identification of research priorities related to the changes in ALS communication including the use of Augmentative and Alternative Communication (AAC).

Methods: Two focus groups of plwALS at early and late stages of change to speech intelligibility were carried out as a Patient and Participant Involvement (PPI) exercise. The transcriptions of these groups were analysed thematically and compared between groups.

Results: Aspects of anticipation, preparation, adaptation and partnership were identified as key to dealing with communication change as a result of ALS. In particular the involvement of partners was clearly significant, as was the impact on them as well as the plwALS.

PlwALS successfully contributed to focus groups and the process of group discussion about communication itself appeared constructive.

Conclusions: Research and new interventions should focus further on how to support the partners of plwALS. Future research with plwALS should place AAC strategies and technology in the context of wider communication and investigate how best to support the anticipation, preparation and adaptation to communication change. Specific areas of research need relating to this support are suggested.

Keywords: communication; AAC; communication aid; augmentative communication

Introduction

Amyotrophic lateral sclerosis (ALS), also known as motor neuron disease (MND), is an incurable disorder in which survival following symptom onset is around 3 years [1]. Individuals succumb to a rapidly progressive degeneration of motor neurons. The consequences are a progressive weakness of limb muscles, loss of speech and swallowing, and respiratory failure. The annual incidence is 1.5-2.5 per 100,000 [2] with 6000 individuals affected in the UK at any one time.

Speech problems (dysarthria) resulting in problems with intelligibility occur in more than 80% of people living with ALS (plwALS) [3]. Approximately one third of people with ALS experience bulbar MND [4], an aggressive form of the disease affecting speech and swallowing muscles early in the disease process. Speech deterioration is cited by

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3 plwALS as one of the most problematic symptoms [5]. The initial period of dysarthria
4 appears to have a strong impact on quality of life [6, 7] and in the longer term the
5 psychological effects of communication change on plwALS and family members can be
6 profound but are often overlooked [8]. Communication is rated by plwALS as a key
7 domain for independence [9]. Additional communication difficulties are associated with
8 changes in cognition [10]. These include impairment of fluency, executive function,
9 language and memory [11].
10

11 While many plwALS lose their ability to communicate verbally, this does not mean
12 losing communicative abilities altogether [12]. Many plwALS rely on augmentative and
13 alternative communication (AAC) strategies and technologies [13]. These encompass a
14 wide range of electronic and non-electronic approaches which may be aided or unaided.
15 There is a notably high AAC acceptance rate by plwALS [14] with reports that 46% of
16 plwALS still use AAC technology within one week of end of life [15]. Recent evidence
17 associates early AAC intervention for plwALS with higher longitudinal quality of life for
18 patients and carers [16]. AAC systems appear to improve or at least stabilize quality of life
19 and mood in plwALS suffering from dysarthria [7]. Professional guidelines reflect this
20 preference for early referral for AAC support (National Institute of Clinical Excellence,
21 2016).
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25 Several studies have examined perceptions of communication and AAC by plwALS
26 and their carers. There is much support for the benefits of AAC [7, 17] although some
27 evidence suggests that it may not necessarily support the full range of communicative
28 functions, including social closeness [18] and communicating with health professionals
29 [19]. Spouses describe unique changes in communication styles as their partners begin to
30 use AAC strategies and technology [8].
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33 Significantly, the communication needs of plwALS change over time. This might
34 typically be described as a spectrum covering people with mild dysarthria, who use their
35 speech and are understandable to most people, to those with little or no intelligible speech
36 who may be totally reliant on AAC to communicate. This transition has to date received
37 little attention [13, 20]. Inevitably communication changes as end of life approaches, with
38 a decrease in all modes of communication including natural speech, gesture, and AAC [21].
39
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41 There is no doubt that that AAC is viewed as important by plwALS and their
42 significant others. What we have yet to establish are expectations of communication and
43 change over time by plwALS, what is most important to people about their communication
44 changes, how best to support these changes, and what interventions to support
45 communication we should be researching. At present much of the evidence is survey or
46 questionnaire based with a focus on the use of AAC rather than communication between
47 plwALS and others.
48

49 The involvement of people with communication impairments in research (i.e. not
50 just as participants) has been promoted and evidenced in areas such as aphasia [22, 23]
51 and dementia [24]. This forms part of a wider initiative to actively support Public Patient
52 Involvement (PPI) when developing research questions and priorities [25]. To date
53 engagement with plwALS and associated speech problems in the research process itself
54 has been notable absent.
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3 The work described here was designed and implemented as PPI with the aim of
4 involving plwALS in the scoping and identification of research priorities related to the
5 changes in communication that are symptomatic of ALS. The intended outcome of this
6 work was to establish topics and areas of research need as described by plwALS and their
7 partners in order to inform the design of future research and AAC technology. In addition
8 the work intended to trial the use of focus groups [26] with participants, grouped by the
9 symptomatic stage of their disease progression, who had difficulty with speaking.
10

11 **Method**

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13
14 Recruitment of participants was carried out via a single UK ALS centre. The study was
15 approved by the management of the UK ALS centre within which it was carried out.
16 PlwALS known to the centre and who had previously indicated that they could be
17 contacted about PPI opportunities were screened by a member of the ALS Centre care
18 team based on their last recorded ALSFRS recorded speech score. Those with a score of 3
19 (“detectable speech disturbance”) or 4 (“Normal speech process”) were assigned to Group
20 1 while those with a score of between 0, 1 or 2 on the scale (‘loss of useful speech’ to
21 ‘intelligible with repeating’) were assigned to Group 2.
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25 Potential participants in each of these groups were contacted about the focus
26 groups by way of an invitation letter and consent form. Individuals who responded to this
27 letter were contacted by telephone and invited with their partners or carers to the
28 appropriate focus group meeting. Transportation expenses to the centre were offered to
29 participants. Where participants were not able to physically sign the consent forms,
30 consent was confirmed using the individual’s communication method and this was
31 recorded as witnessed by their partner and one of the focus group facilitators.
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34 **Data Collection**

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36
37 Topic guides (included as online appendix) were developed for each focus group based on
38 a previous literature review of the topic and on the intended focus of consultation. The
39 guides were developed and then revised through discussions with an expert panel
40 comprising a representative from the Motor Neurone Disease (MND) Association - a UK
41 organisation with the role of supporting plwALS, a service user representative, a local and
42 specialist AAC practitioner, an ALS AAC researcher and an ALS specialist neurologist. The
43 questions for each group aimed to address the same aspects of the topic although some
44 wording changes were required to reflect the cohort in each group. It was decided not to
45 simply present participants with a list of possible research ideas for acceptance or
46 rejection but rather to provide space for discussion on communication in order to allow
47 potential research ideas to emerge. Topic guide questions were not posted in advance as it
48 was felt this might steer the conversation too significantly. Participants were aware of the
49 topic of the focus group prior to the meeting and at the end of the focus group participants
50 were offered the opportunity to send additional responses to the questions if they felt that
51 they had anything to add that they had not been able to say.
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55 Two focus groups were carried out at the ALS care centre in October and
56 November 2015. The focus groups were led by the first and second authors who are both
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3 experienced at carrying out focus groups with individuals with speech and communication
4 difficulties. The third author, a consultant neurologist at the centre introduced the
5 sessions to participants, and the session was also attended by the local representative of
6 the MND Association in a pastoral and supportive capacity.
7

8 The focus groups were video as well as audio recorded to assist with transcribing
9 any non-verbal communication. The recordings were transcribed using a commercial
10 transcription service and checked and anonymised by the first author.
11
12

13 ***Analysis***

14
15 The broad method of analysis was that of a thematic analysis [27] of the transcriptions
16 using a framework analysis approach. NVivo version 10 (QSR International) was used as
17 the data management and coding tool.
18

19 The first author initially coded the transcripts into descriptive themes, these
20 themes were then reviewed and developed into a thematic framework. The coding and
21 framework was then reviewed by the second author with minor revisions made. A
22 description of the themes was then distributed for comment to a carer and MND
23 Association representative who suggested no further revisions. Finally, the first and
24 second authors compared themes between the two groups.
25
26

27 **Results**

28
29 Three plwALS attended the first focus group of which two attended with their partners
30 (the third participant's partner was unable to attend). Three plwALS and partner dyads
31 attended the second focus group (for those living with ALS and affected speech) with two
32 additional partners of individuals who had lived with ALS and had since died also
33 attending. All participants with ALS lived with their partners in their own homes. Details
34 of participants are provided in Table 1.
35
36

37
38 INSERT TABLE 1 HERE.
39

40 The data are presented below by presenting the analysis of the two separate groups.
41
42

43 ***Group 1: PlwALS with unaffected or minimally affected speech***

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45 This group comprised five participants: three plwALS and two of their partners.
46
47

48 *Anticipation of changes to communication*

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50 Participants were aware of and anticipating changes in their communication but not all
51 wanted to acknowledge it
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56 Most were aware through having seen others at a later stage of the disease while some
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3 had also actively sought information through the MNDa and social networking.
4 Anticipation of AAC use was described negatively in terms of the time it takes to
5 communicate, the portability of equipment and the effort required to use equipment,
6 including potential fatigue.
7

8
9 *Preparedness: Preparation for changes*

10 On the whole, the group was very determined to “*find ways and means of doing things*” and
11 “*fight*” the process of the disease. There was however some sense of fear about upcoming
12 potential changes to speech. The group had experienced this fear and also already
13 experienced frustrations with the changes in their speech (even though they may be
14 classified as having good intelligibility). Not all participants had considered or made
15 preparations for changes in communication but many had focused significant energy and
16 emotion on this.
17
18

19 There was a very strong motivation for some to prepare by voice banking (creating a
20 personalised synthetic voice) and aspects of voice identity were discussed as highly
21 significant to some. This preparation was discussed “*in spite*” of some challenges in the
22 process which participants described as ‘*hard work*’ and also in needing to complete the
23 process before they noticed any significant changes in their speech. As well as the
24 potential technical and process improvements to voice banking this discussion highlighted
25 a need for more nuanced understanding of voice identity and also ongoing support: *I don’t*
26 *think it’s any good professionals going away and saying ‘well you can do this and you can do*
27 *this, you go on the computer and you do model talker or you can do video diaries for your*
28 *children or grandchildren’. You need support with that because there’s enough going on in*
29 *your life and things are difficult enough on a day to day basis without expecting people with*
30 *MND to sit down and do those things on their own because everyday life is a challenge*
31 *without, you know, expecting people to just go and do that on their own. It’s something*
32 *somebody needs to do with you, not just say ‘go away and do it’.”*
33
34
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38 Most participants had not considered the concept of preparing spoken or written
39 phrases in advance before but some felt that preparing by teaching the system their
40 individual language and mannerisms of speech could be of benefit to research and develop
41 further. The effort required to record the ‘*meaningless*’ phrases required for voice banking
42 was noted by one participant who felt this effort could be better used to record phrases
43 with personal meaning.
44

45 Using video or audio to leave a legacy was also felt particularly pertinent by those
46 with children and another aspect warranting further support and investigation.
47

48 How much participants wanted to know, or to not know, about communication
49 changes appeared to be an individual concept. One participant, who had felt the most
50 trepidation about preparing, felt more direction about speech and communication at early
51 stages from a consultant would have made a difference to her actions. For some Twitter
52 and social networking were key sources of information and community but others did not
53 know how to access information in this way and some had been encouraged not to look on
54 the internet:
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3 *they all tell you 'don't look on the Internet'. Why not? The Internet is a wonderful tool, you*
4 *just have to pick and choose what websites you look at*
5

6 All in the group felt that the experience of discussing communication during the
7 focus group had been positive and in itself could be investigated as a form of support or
8 therapy. Participants described that meeting others with the condition could be an
9 empowering and an effective way of sharing information and strategies. Most participants
10 had met others with ALS before, however meeting someone at a different stage in the
11 condition could be harrowing and depended on the psychological and emotional state and
12 approach of an individual in coping with the diagnosis.
13

14
15 *Feelings about, and response to change:*
16

17
18 All in the group had detected changes in their speech and for some this was the first
19 indication of a problem that led to diagnosis. These changes could appear small to others
20 listening but were perceived as significant changes to the individuals and it was suggested
21 that this was poorly understood.
22

23 *(on going to clinic) He knows that his speech has deteriorated, I know that it's deteriorated*
24 *and I know that he sounds different and J described it as sometimes he feels like he's talking*
25 *through his nose and he feels all clogged up inside. But yet when he goes to the clinic they*
26 *quite often say 'how's your swallowing and how's your speech?' and J says 'well my speech is*
27 *getting worse' and they say 'it sounds normal to me'. "J says 'well my speech is getting worse'*
28 *and they say 'it sounds normal to me'.*
29
30

31 All had had problems communicating with others and had noticed changes in how
32 others perceived them, or communicated with them. Participants described experiencing
33 frustration with changes in their speech, even though they were classified as having 'good'
34 intelligibility. Some participants had seen others with ALS speaking and found this
35 distressing. There was some sense of fear about upcoming potential changes to speech.
36

37
38 Throughout the discussion of change, support of partners also seemed to be key to
39 all in coping with the diagnosis and considering the future. In a number of cases these
40 attitudes to preparation and the future were felt differently between partners.
41

42 ***Group 2: Those living with ALS with affected speech*** 43

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45 This group comprised eight participants: three plwALS who used AAC strategies and their
46 partners and two partners of individuals who had died as a result of ALS.
47

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49 *Anticipation of changes to communication*
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51 Participants highlighted a fresh appreciation of the importance of communication and the
52 role it plays in independence and quality of life.
53

54 *You need some way of communicating those emotions, those feelings, and it helps you to cope*
55 *with the MND.*
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3 Participants described that learning to use a communication aid took time and
4 depended on the individual. As well as learning to use the device there were challenges in
5 learning how to best to use it to communicate. No participants described having
6 experienced formal support in learning to use the communication aid, or communicate
7 with it and felt that this process could be better supported and researched.
8

9 Once learnt, features such as word prediction and pre-composition of phrases
10 were described by some as beneficial but that could be improved.
11

12 The changes to communication that participants experienced were varied and
13 included a number that they had not anticipated. The lack of naturalistic communication
14 had a significant impact on both partners in a couple. Participants had not anticipated the
15 emotional and psychological impact of changes to communication, and had not
16 experienced any support in dealing with this.
17

18
19 *it's getting to used to inside not being able to join in that banter in the pub, not being able*
20 *just to respond to something that's been said ... it's so important to me , and I'm sure to you,*
21 *to know that somebody understands that feeling of loss.*
22

23 24 *Preparedness*

25
26 Some participants had tried using communication aids before they needed them whereas
27 others had waited until they had to use them or until there was a 'tipping point' that made
28 them use one. One plwALS described being proactive in seeking out information about
29 communication aids (but not other equipment he may need) "*Because technology is*
30 *wonderful but it takes a while to learn how to use it yourself.*" Other participants
31 consciously or unconsciously chose not to consider future communication changes. No
32 participants described a structured approach to preparing for changes to communication.:
33 "*No, just pick it up really as you go along. You stumble along*".
34
35

36 The group felt it was not possible to prescribe a set 'journey' of communication aid
37 use as it depended on many different factors. The key was being able to use the
38 appropriate aid at the right time. The group had varying opinions as to what information
39 about changes in communication should be provided – some felt they would want to
40 know all the information early, others wanted it 'just in time': "*when he first started, a*
41 *speech therapist came with all these machines, all these computers but, you know, at that*
42 *point he was speaking not too bad really, you know, quite well.*"
43
44

45 This group did not focus greatly on voice banking and had mixed views – for some
46 this would have been a big factor in improving the communication aid and for others this
47 made no difference. Some felt that hearing an individual's voice 'back' was emotionally
48 very hard: "*It just emphasises even more that R's voice has gone*".
49
50

51 Some in the group were aware that devices could learn through word prediction
52 how an individual used them. One example of not being able to transfer learnt word
53 predictions from one AAC system to another highlighted the challenge and further
54 development required related to this aspect of preparation.
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Adapting to changes in communication

The use of a synthesised voice itself was discussed as being different from speaking. The concept of identity was challenging and changing with the use of communication aids and perceived as not well understood. *"That's not you speaking, it might be you manipulating the pen but it's not you speaking" and "It is so frustrating. You feel within your head what you are saying is clear. We have tried to carry on with life as normal. It took me a long time to accept that it was me."*

There was a preference to use speech for as long as it was at all possible, even when this was very challenging. Experience of loss of speech as the condition progresses is challenging and everyone around the person has to adapt to this. Partners often acted as translators or voices despite the change in relationship this creates.

For some the change in communication had impacted on their social network and with whom they communicated although some described this as a temporary restriction whilst they developed strategies to cope or change attitudes of those around them. Couples adopted different strategies to managing the changes in communication and in implementing strategies to adapt and again, none had been taught or supported in these.

The role of the partner and the impact on them

It was clear throughout the group that partners have a key role in communication. The difficulty with communicating challenges the tool that most people use as part of coping with problems – talking about them with others.

Partners described the emotional impact in not being able to talk to their loved ones in the same way as previously.

I do need to toughen up because yeah, it hurts that you can't be more expansive.

Partners also described having changed communicative roles within the partnership. Communication difficulties changed the content and style of conversations but also gave partners the role of *"anticipation and the interpretation"* of speech and utterances from communication aids : *" it's something that I'm having to get used to is shortening things, like you say just saying 'tea' or whatever. You do abbreviate things now and sometimes I find it a bit difficult. Like coming here you said you've got to ring five people. That would previously have been a 'I'm really sorry but would you mind' and it's blunt isn't it? Of course it is but that's just something else for me to get used to. It's not R being uncaring."*

Partners also had to learn new skills to help mediate communication for the plwALS. These skills seemed to not be recognised explicitly by partners as skills, and were not taught or coached – they were an adaption to the situation. *" I can pick up quite a lot of his conversation and pick things up and put my own words in between it if I can get odd words if we know what we're talking about. It's if he suddenly goes onto a different subject, then I've lost it, 'well we weren't talking about that!'"*

Discussion

The motivation behind this work was to ensure that plwALS were more involved with communication impairment research. The intended outcome of the work reported in this paper was to establish topics and areas of research need as described by plwALS and their partners related to changes in communication arising from ALS. The original anticipated outcome was identified research priorities that would relate to AAC provision. However the actual outcomes focused more on the wider communication journey with four common themes identifying research priorities emerging across the two groups who were at different stages of the symptoms of the disease:

- Anticipation: Looking into the future and predicting changes to communication.
- Preparedness: Preparing (or not) for these changes.
- Adaptation: Response and adaptation to the changes in communication.
- Partnership: The role of the partner and the impact on them.

For both the plwALS and their partners there was a significant psychological impact of the anticipation of communication changes that appeared under supported and researched. The UK National Institute of Clinical Excellence (2016) suggest early referral for AAC support, however from this work it was clear that there was scope to improve the approaches to information provision and support related to communication changes as well as use of AAC. A more nuanced investigation into the best methods of supporting anticipation of communication changes is warranted including the consideration that communication may require more clinical attention earlier in the ALS journey.

The first group of plwALS, who had relatively unaffected speech, were perhaps understandably much more focused on what they saw as aspects of preparedness. In particular voice and message banking were clearly a focus for this group. The different attitude towards this element of preparedness by the second group was marked however. Both groups recognised the amount of individual work required for a successful outcome. It is clear that the concept of identity is of importance to plwALS and that personalised voice synthesis can have a significant impact for some. It is also known that the optimal time in terms of the level of dysarthria of a plwALS using the current voice banking is critical to the quality of the synthesised voice [28]. Our findings may suggest that for some the focus of preparation effort might be more successfully placed elsewhere – for example in psychological support and other more practical preparation of both the individual and their partner.

Regarding adaptation, there is a clear realisation that participants need to adapt to different modes of communication. This entails both learning new skills, with partners learning how best to carry out the new roles they adopt as conversational mediators and translators, and plwALS learning how to integrate AAC methods with existing modalities as a new way of accomplishing communication.

Participants not yet using AAC perceived the future use of AAC negatively – this may highlight that AAC design issues such as speed and naturalness of communication remain pertinent and/or that further investigation is needed around how these initial perceptions may affect future AAC use and success. Participants identified some specific

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3 AAC developments such as the ability to prepare for and adapt device usage more
4 effectively by better learning the written language of the plwALS.
5

6 Adaptation was most obviously observed in terms of adaptation to the physical
7 access to AAC technology (e.g. through eye-gaze selection) but should also be understood
8 in emotional, psychological and interactive terms [29, 30]. The value of AAC systems for
9 plwALS has, in the past, been considered self-evident. However, the relative merits of
10 different systems and their wider impact on communication and relationships has only
11 recently begun to be established and warrants further work. The understanding of AAC as
12 part of a wider communicative process, by professionals as well as plwALS, may also
13 require further consideration.
14
15

16 The integral role of partners to the communication process is evident but appears
17 under researched given its prominence in these data. The fact that plwALS and their
18 partners might feel differently about communication invites a more nuanced view of
19 family dynamics which may well impact on the success or otherwise of adaptive
20 communicative strategies as the disease progresses. Changes in levels of communicative
21 spontaneity, for example, may place additional emotional pressures on existing
22 relationships, as may the unexpected finding that some significant others may find hearing
23 their partner's voice (via voice banking) difficult to cope with. What is clear is that being a
24 partner involves changes in communication responsibilities such as becoming a
25 conversational mediator. How this plays out in practice has been evidenced in part [31,
26 32] but requires further investigation. Whilst it is important to consider the
27 communication needs of the individual themselves it is clear that there is inadequate
28 support for the partner who needs to learn a range of new skills, cope with their changed
29 role and also the psychological impact of their partner's changed ability to communicate –
30 it is clear that this is also an under researched aspect of communication change in ALS.
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34 A secondary aim was to trial the use of focus groups with participants who had
35 difficulty with communication grouped by the symptomatic stage of their disease
36 progression. Others have demonstrated that, whilst potentially challenging, meaningful
37 involvement is possible with individuals with other forms of communication disability
38 [22] and here we have extended this to plwALS. We have shown that focus groups can
39 work for PPI involvement and that clearly plwALS can make an important collective
40 contribution to the research process. What we must do now is look to how best extend this
41 contribution to sustain engagement, possibly through virtual engagement as well as face-
42 to-face.
43
44

45 Feedback from participants and the facilitators highlighted the constructive
46 benefits of discussing communication and its challenges within a small group setting. It is
47 not common for people to discuss communication and speech deterioration with others in
48 this way. There are established self-help groups for people with non-progressive
49 conditions but progressive speech loss invokes negative change, something that might be
50 viewed as uncomfortable or distressing. With appropriate facilitation the experiences
51 reported here suggest that there is a role for small group support and possibly group
52 intervention for plwALS with specific reference to communication.
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Conclusions

Speech deterioration and the use AAC form the basis of most communication related research in the field of ALS. The evidence generated over the past 30 years is meaningful but lacks critical engagement with plwALS to inform both the direction and design of the research itself. Whilst the challenges to this engagement are significant there is little doubt that plwALS experiencing changes to their speech can make an important contribution. The PPI findings reported here reveal that aspects of anticipation, preparation, adaptation and the involvement of partners require further investigation.

The results of this work imply that we should extend the existing research focus on AAC systems and their use by plwALS to include the whole process of communication change and support. This includes how the use of AAC, of whatever type, is approached and understood as a process rather than a one-off solution. Feedback reported here suggests that one key question we should be asking is not 'whether AAC is useful?' but rather 'how can communication best be supported?'. This question places AAC provision and intervention within a wider context of communication; not treating any form of AAC as a straightforward replacement for unintelligible speech but rather as one element of a complex support process.

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Table 1. Participant Details

Group 1: PlwALS with unaffected or minimally affected speech				
P1	plwALS	Male	40-50	Speech. Some partner support. Powered wheelchair user – independent control via joystick.
Pt1	Partner	Female	40-50	-
P2	plwALS	Female	60-70	Speech. Ambulant, with assistance in stand/sit transfers.
Pt2	Partner	Male	60-70	-
P3	plwALS	Male	60-70	Speech. Ambulant with walking stick for support.
Group 2: Those living with ALS with affected speech				
P4	plwALS	Male	50-60	Ipad Mini with ClaroCom App. Direct Access. Writing. Speech (with partner support). Ambulant.
Pt4	Partner	Female	50-60	-
P5	plwALS	Male	40-50	Smartbox Powerbox with The Grid 3 software & Text based keyboard and phrase package. EyeGaze access. Eye pointing (with partner support) Powered wheelchair user (partner control)
Pt5	Partner	Female	40-50	-
P6	plwALS	Male	60-70	Writing. Speech (with partner support). Ambulant
Pt6	Partner	Female	60-70	-
Pt7	Partner	Male	60-70	-
Pt8	Partner	Male	60-70	-

Implications for Rehabilitation.

- People living with ALS (plwALS), are rarely involved in setting the research agenda in the areas of speech and augmentative and alternative communication.
- Enabling plwALS to contribute to research, even those with no speech, is feasible with appropriate support.
- Feedback indicates that communication change and AAC are experienced in different ways by plwALS
- Research and intervention should focus on how to support the anticipation, preparation and adaptation to communication change for plwALS

For Peer Review